



## **DEPARTMENT OF HEALTH AND HUMAN SERVICES**

### **Health Resources and Services Administration**

#### **Meeting of the Advisory Committee on Heritable Disorders in Newborns and Children**

**AGENCY:** Health Resources and Services Administration (HRSA), Department of Health and Human Services.

**ACTION:** Notice.

**SUMMARY:** In accordance with the Public Health Service Act, and the Federal Advisory Committee Act, this notice announces that the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC or Committee) has scheduled a public meeting. Information about the ACHDNC and the agenda for this meeting can be found on the ACHDNC website at <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>.

**DATES:** Thursday, February 9, 2023, from 9:30 AM to 3 PM Eastern Time (ET) and Friday, February 10, 2023, from 9:30 AM to 2 PM ET.

**ADDRESSES:** This meeting will be held via webinar. While this meeting is open to the public, advance registration is required. Please visit the ACHDNC website for information on registration: <https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html> by the deadline of 12 PM ET on February 8, 2023. Instructions on how to access the meeting via webcast will be provided upon registration.

**FOR FURTHER INFORMATION CONTACT:** Alaina Harris, Maternal and Child Health Bureau, HRSA, 5600 Fishers Lane, Room 18W66, Rockville, Maryland 20857; 301-443-0721; or [ACHDNC@hrsa.gov](mailto:ACHDNC@hrsa.gov).

**SUPPLEMENTARY INFORMATION:** ACHDNC provides advice and recommendations to the Secretary of Health and Human Services (Secretary) on the development of newborn screening activities, technologies, policies, guidelines, and programs for effectively reducing

morbidity and mortality in newborns and children having, or at risk for, heritable disorders. The ACHDNC reviews and reports regularly on newborn and childhood screening practices, recommends improvements in the national newborn and childhood screening programs, and fulfills requirements stated in the authorizing legislation. In addition, ACHDNC's recommendations regarding inclusion of additional conditions for screening on the Recommended Uniform Screening Panel (RUSP), following adoption by the Secretary, are evidence-informed preventive health services provided for in the comprehensive guidelines supported by HRSA pursuant to section 2713 of the Public Health Service Act (42 U.S.C. 300gg-13). Under this provision, non-grandfathered group health plans and health insurance issuers offering non-grandfathered group or individual health insurance are required to provide insurance coverage without cost-sharing (a co-payment, co-insurance, or deductible) for preventive services for plan years (i.e., policy years) beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

During the February 9-10, 2023, meeting, ACHDNC will hear from experts in the fields of public health, medicine, heritable disorders, rare disorders, and newborn screening. Agenda items include the following:

- 1) Presentation of the final evidence-based review report on the Krabbe disease condition nomination for possible inclusion on the RUSP. Following this report presentation, the ACHDNC expects to vote on whether to recommend to the Secretary adding Krabbe Disease to the RUSP;
- 2) An update by the ACHDNC Prioritization and Capacity workgroup;
- 3) A possible presentation from the Center for Disease Control and Prevention's Enhancing Data Driven Disease Detection in Newborns Project;
- 4) A potential update on the HRSA-funded Newborn Screening Interoperability Programs;
- 5) A presentation on the Blueprint for Change, which outlines an agenda for advancing the system of services for children and youth with special health care needs (see

<https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn/blueprint-change>);

- 6) Workgroup updates; and
- 7) A potential update on the Duchenne muscular dystrophy condition nomination and a potential vote on whether to move it forward to full evidence-based review, which, depending on the strength of the evidence, could lead to a future recommendation to add this condition to the RUSP.

The agenda for this meeting includes a potential vote to recommend a nominated condition (Krabbe Disease) be added by the Secretary to the RUSP. In addition, as noted in the agenda items, the Committee may hold a vote on whether or not to recommend a nominated condition (Duchenne muscular dystrophy) to full evidence-based review, which may lead to a recommendation to add or not add this condition to the RUSP at a future time.

Agenda items are subject to change as priorities dictate. Information about the ACHDNC, including a roster of members and past meeting summaries, is also available on the ACHDNC website.

Members of the public also will have the opportunity to provide comments on any or all of the above agenda items. Public participants may request to provide general oral comments and may submit written statements in advance of the scheduled meeting. Oral comments will be honored in the order they are requested and may be limited as time allows. Subject to change: members of the public registered to submit oral public comments on Krabbe Disease are tentatively scheduled to provide their statements on Thursday, February 9, 2023. Members of the public registered to provide oral public comments on all other newborn screening related topics are tentatively scheduled to provide their statements on Friday, February 10, 2023. Requests to provide a written statement or make oral comments to the ACHDNC must be submitted via the registration website by 12 PM ET on Thursday, January 26, 2023. Written

comments will be shared with the Committee, so that they have an opportunity to consider them prior to the meeting.

Individuals who need special assistance or another reasonable accommodation should notify Alaina Harris at the address and phone number listed above at least 10 business days prior to the meeting.

**Maria G. Button,**

*Director, Executive Secretariat.*

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